

## Fact Sheet:

# Informal/Family Caregivers

### Overview

*The terms informal caregiver and family caregiver refer to unpaid people, such as family members, friends and neighbors, who provide care.*



What is the estimated value of informal caregiving?

Family caregiving is a critical piece of our long-term care system. In fact, family and other unpaid caregivers provide nearly 80% of all long-term care in this country.

Nationally, nearly one out of every four households (22.4 million households) is involved in caregiving to someone over the age of 50.

Fifty-two million informal and family caregivers provide care to someone aged 20+ who is ill or disabled. Nearly 30 million family caregivers provide personal assistance to adults with a disability or chronic illness. Nearly seven million Americans are long-distance caregivers for older relatives.

Just over half of all caregivers for persons aged 50+ are employed full-time and almost two-thirds are employed either full- or part-time.

Caregivers spend an average of 4.5 years providing care. The majority provides unpaid assistance for one to 4 years; 20% provide care for 5 years or longer.

The care provided by family members helps people with illness or chronic disability to stay in their own homes and communities. This family care reduces the costs incurred by Washington State, faced with the challenge of paying for long-term care for low-income residents.

In Washington State, more than 570,620 family caregivers are helping adults who have chronic illnesses or serious disabilities.

More men are assuming the caregiving role. It's estimated that there are 228,000 male caregivers in Washington State

If the services provided by informal caregivers had to be replaced with paid services, it would cost an estimated \$257 billion per year.

Researchers estimate that the cost of informal caregiving in terms of lost productivity to US businesses is \$11.4 billion annually.

Each year in Washington State, family caregivers provide 611,000,000 hours of care, at a value of over \$5.4 billion.

### Impact on caregiver health

A study of older spousal caregivers found that caregivers who experience mental or emotional strain have a 63% higher risk of dying than non-caregivers. Other studies show that an estimated 46% - 59% of caregivers are clinically depressed.

Stress in family caregivers is inversely correlated to income: the less income a caregiver has, the more stress he or she is likely to experience.

Caregivers use prescription drugs for depression, anxiety and insomnia two to three times as often as the rest of the population.

Caring for an ill family member can be physically demanding and exhausting, and can leave the caregiving feeling overwhelmed, frustrated, or fearful. Research has shown that caregiver stress, alcohol or substance abuse, and emotional and/or financial problems are factors in many instances of elder abuse.

### Caregiver Support and Assistance

About one-half of primary caregivers provide care with no outside assistance whatsoever.

Only an estimated 10% to 20% of family caregivers use formal services through public or private agencies.

### Why support family caregivers?

Family caregivers are experiencing change. An increasing number of women now work outside the home. Families' geographic mobility and a decrease in family size means there are fewer family members around to share in caregiving tasks. And, 44% of the sandwich generation – Americans between the ages of 45 and 55 – currently experience both sides of the caregiving spectrum with children under 21 as well as living parents, in-laws, or both.

In 1990, there were eleven potential caregivers for each person needing care. By 2050, that ratio will be 4:1.

Despite the complexities of everyday life, families want to stay involved. Research indicates that in some cases families continue caregiving even at the expense of their own health and well-being. Studies suggest that relatively low-cost supportive services for family caregivers can not only reduce the stress experienced by family caregivers, but can result in delayed nursing home placement for the person needing care.

### Respite Care Services Program

The Respite Care Services Program has served family caregivers throughout Washington State since 1989 and has an annual budget of \$2,758,000. The program targets family and other unpaid caregivers assisting adults with a functional disability. Respite services are provided both in-home and in residential and adult day services settings on a planned or on an emergency basis.

### Family Caregiver Support Program

*"The caregiver specialist helped arrange services when I thought there were none available ... she has tackled some hefty research jobs for me ... I can't tell you how much it means to me to hear her voice on the other end of the phone."*

*"This has been a life saver."*

Started in October 2000, the Family Caregiver Support Program offers:

- Information about services
- Assistance in gaining access to services
- Caregiver support groups and counseling
- Caregiver training and education
- Respite Care
- Supplemental Services

DSHS' Aging and Disability Services Administration administers the program that is implemented locally by Area Agencies on Aging. State legislation provides an annual budget of \$631,000. The federal Older Americans Act contributes \$2,862,961 through the National Family Caregiver Support Program to support family caregivers of older adults. This program also serves kinship caregivers -- relatives age 60 or older, caring for children under the age of 19, as well as older caregivers caring for children with a developmental disability. To find the program in your area, go to [www.adsa.dshs.wa.gov](http://www.adsa.dshs.wa.gov) or call toll-free 1- 800-422-3263.

### Relatives as Parents Program

*The Relatives as Parents Program website*

<http://parenting.wsu.edu/relative/index.htm> provides information on support groups and kinship resource guides, a video lending library, media coverage, and links to other related websites.

An estimated 35,341 grandparents in WA State are the primary caregivers raising their grandchildren. In addition, aunts, uncles and other relatives are also raising children. The greatest issues facing kinship caregivers in WA State include: financial needs, legal and bureaucratic barriers, social service needs and information gaps.

Currently more than 40 support groups are available to grandparents and relatives who are raising children.

The **Kinship Caregivers Support Program**, funded by the WA State Legislature in 2004 at \$5000,000, provides one-time financial assistance to kinship caregivers (of any age) who are in greatest need. To find the program in your area call 1-800-422-3263 or go to [www.adsa.dshs.wa.gov/topics/caregiving/kinship.htm](http://www.adsa.dshs.wa.gov/topics/caregiving/kinship.htm).

There are several very helpful free publications for kinship caregivers:

***Relatives as Parents Program-A Resource Guide for Relatives Raising Children in Washington State***, provides information on public and private resources. It is available by going to [www.prt.wa.gov](http://www.prt.wa.gov), clicking on General Store and locating the booklet's publication number, DSHS 22-996X.

***Did you know about the following services and supports for grandparents and relatives raising children in WA State?*** (DSHS 22-1120) This four page pamphlet lists a variety of programs that offer benefits and services to relative caregivers, plus contact information. You can order English and Spanish copies from the Dept. of Printing. A pdf version can be downloaded from the ADSA website in the following languages: English, Cambodian, Chinese, Korean, Laotian, Russian, Somali, Spanish, and Vietnamese.

Area Agency on Aging  
Contacts for Family  
Caregiver Support  
Programs

***Consent to Health Care for the Child in Your Care: a Caregivers' Guide*** (DSHS 22-1119) A new law passed by the 2005 Washington State legislature allows adults raising a relative's child to consent to health care. This brochure explains a relative's rights and responsibilities under the new law. English and Spanish copies can be ordered from the State Dept. of Printing. A pdf version of the brochure can be downloaded from the ADSA website in English, Cambodian, Somali, Spanish, and Vietnamese.

***Olympic Area Agency on Aging*** (Clallam, Grays Harbor, Jefferson, and Pacific Counties) Ginny Adams 360/379-5064

***Northwest Washington Area Agency on Aging*** (Island, San Juan, Skagit, and Whatcom Counties) Kim Boon, 360/676-6749

***Snohomish County Long Term Care and Aging Division*** (Snohomish County) John Peterson 425/388-7307

***Aging and Disability Services*** (King County) Margaret Casey 206/684-0662

***Pierce County Aging and Long Term Care*** (Pierce County) Connie Kline 253/798-3782

***Lewis/Mason/Thurston Area Agency on Aging*** (Lewis, Mason, and Thurston Counties) Carrie Petit 360/664-3162 x147

***Southwest Washington Agency on Aging*** (Clark, Cowlitz, Klickitat, Skamania, and Wahkiakum Counties) Kristrun Grondal 360/694-6577

***Aging & Adult Care of Central Washington*** (Adams, Chelan, Douglas, Grant, Lincoln, and Okanogan Counties) Lori Kostors 509/886-0700

***Southeast Washington Aging and Long Term Care*** (Asotin, Benton, Columbia, Franklin, Garfield, Kittitas, Yakima, and Walla Walla Counties) Laurie Camp 509/965-0105

***Yakama Nation Area Agency on Aging*** (Yakama Reservation) Marie Miller 509/509-865-7164

***Aging & Long Term Care of Eastern Washington*** (Ferry, Pend Oreille, Spokane, Stevens, and Whitman Counties) Debi Levin-Stankevich 509/458-2509

***Colville Indian Area Agency on Aging*** (Colville Reservation) Reva Desautel 509/634-2759

***Kitsap County Division of Aging & Long Term Care*** (Kitsap County) Tawnya Weintraub 360/337-7068

To find more information about caregiving or to order the free *Caregivers' Handbook*, go to [www.adsa.dshs.wa.gov](http://www.adsa.dshs.wa.gov) or call toll-free 1-800-422-3263.